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IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF FOR AMICI CURIAE AMERICAN ACADEMY OF PEDIATRICS, AMERICAN PEDIATRIC SOCIETY, SOCIETY FOR PEDIATRIC RESEARCH, ASSOCIATION OF MEDICAL SCHOOL PEDIATRIC DEPARTMENT CHAIRMEN AND WESTERN ASSOCIATION OF CHILDREN'S HOSPITALS

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QUESTION PRESENTED

Whether Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, permits the Department of Health and Human Services to regulate individual medical treatment decisions concerning critically ill infants or to regulate compliance with state reporting requirements, particularly in the absence of a record establishing that any improper activity by recipients of federal financial assistance—those covered by the Act—has occurred?

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The American Academy of Pediatrics (the "Academy"), the American Pediatric Society, the Society for Pediatric Research, the Association of Medical School Pediatric Department Chairmen and the Western Association of Children's Hospitals submit this brief *amici curiae* in support of Respondents American Hospital Association, *et al.* and in opposition to the brief filed by Secretary Margaret M. Heckler ("the Secretary") of the Department of Health and Human Services ("HHS"). It is accompanied by written consents from Petitioner and Respondents.

INTEREST OF AMICI CURIAE

The Academy is a non-profit organization of more than 28,000 board-certified pediatricians who are the individuals most intimately involved in caring for seriously ill infants. Most of the Academy's members practice medicine in hospitals which would be affected by any decision of this Court concerning the application of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, to medical treatment of seriously ill infants. Further, the Academy's Committees on Children with Disabilities and Bioethics have coordinated educational programs on medical treatment decisions involving handicapped children, and have developed statements of bioethical principles for Academy adoption.

The Academy has also been actively involved in judicial and administrative proceedings considering the applicability of Section 504 to medical treatment decisions. The Academy was the lead plaintiff in *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C.), *appeal dismissed*, No. 83-1407 (D.C. Cir. Aug. 4, 1983) ["*AAP v. Heckler*"], which invalidated an "interim final rule" promulgated under Section 504 concerning discrimination against handicapped infants. Second, the Academy commented on proposed rules regarding discrimination on the basis of handicap in medical treatment of infants. These rules, in revised form, are the regulations at issue in this case. 49 Fed. Reg. 1622 (Jan. 12, 1984) (J.A. 11-111).[1]

The American Pediatric Society, the Society for Pediatric Research and the Association of Medical School Pediatric Department Chairmen ("AMSPDC") represent the faculty and leadership of academic pediatric departments. Membership in the American Pediatric Society and the Society for Pediatric Research is conferred on the basis

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[1] J.A. —— refers to the Joint Appendix.

of scholarship, research, and contributions to pediatric education. AMSPDC members are responsible for operating the departments of pediatrics of virtually every major tertiary care center in which neonatal intensive care units are located. This case arises in large degree from the advances in pediatric care made by these physicians which make it possible to extend the lives of many disabled and premature infants.

The Western Association of Children's Hospitals ("WACH") is a non-profit organization of nine hospitals providing most of the tertiary and much of the primary care to seriously ill infants in the western portion of the United States. WACH was founded to promote recognition of the special needs and circumstances of children's hospitals in formulating public health care policy. Members of WACH commented on the proposed rules which, in revised form, are at issue in this case. Thus, WACH and its members have a direct interest in the case currently before this Court.

SUMMARY OF ARGUMENT

Petitioner invokes Section 504 to regulate individual medical treatment decisions involving critically ill infants. She entirely ignores the intrinsic complexity both of the medical conditions suffered by such infants and the medical decision making which accompanies them.

Petitioner suggests a paradigm case in which an infant possesses a static disability on the one hand, and a separate, easily treatable medical condition on the other. In fact, most infants subject to Petitioner's rule suffer from myriad, interrelated medical conditions, none of which can be characterized as static disabilities, and none of which are easily treatable. Moreover, the infants' medical conditions fluctuate continuously, so that the prognoses change from moment to moment. These factors render impossible any determination of "discrimination" under Section 504.

The very language of Section 504, and the case law interpreting it, demonstrate that the statute does not authorize federal intervention into treatment decisions for critically ill infants. Because there exists no "customary" standard of medical care applicable to all infants, it is impossible to determine whether a particular infant is "otherwise qualified" for a particular treatment. Second, the medical treatment decisions Petitioner seeks to regulate involve no "discrimination" by a federally-funded program or activity. Treatment decisions concerning critically ill infants are made by parents, who are not recipients of federal funds. Petitioner's convoluted attempt to involve hospitals in the decision-making process fails, since Section 504 does not require a recipient of *federal* funds to invoke the protections of a *state* child abuse program. Moreover, Petitioner cites no evidence that hospitals are ignoring their state reporting duties. Third, Petitioner's regulations constitute a burdensome and harmful intrusion into ongoing treatment, encouraging painful overtreatment and jeopardizing the quality of care received by the very infants Petitioner purports to protect.

Finally, the legislative history of Section 504 is devoid of any indication that Congress intended the statute to permit federal regulation of individual medical treatment decisions. Further, when Congress ultimately did address the issue of appropriate care for critically ill infants, it specifically decided that such issues should be left to the states.

ARGUMENT

I. PETITIONER'S CONCEPT OF "DISCRIMINATION" UNDER SECTION 504 FAILS TO ACCOUNT FOR THE COMPLEXITY OF MEDICAL CASES AND MEDICAL DECISION MAKING

As pediatricians involved in the daily care of seriously ill infants, *amici* are concerned that Petitioner has dramatically oversimplified the complex medical decision making which she intends to regulate under Section 504. Seriously ill infants typically suffer from complicated and interrelated medical conditions, which can change day to day, hour to hour. Medical decision making involves evaluation of complex and fluctuating factors, and the medical condition to be treated is often inseparable from the putative "handicap"; hence, the notion of "discrimination," which is the core of Section 504, has no application.

A. Seriously Ill Infants Do Not Present Simple, Straightforward Cases

Petitioner premises her Section 504 analysis on the case of the so-called "Baby Doe" infant in Bloomington, Indiana, a child born with several serious disabilities including Down's Syndrome and a tracheoesphageal fistula, an abnormal connection between the trachea and esophagus which prevents normal eating, but which is surgically correctable.[2] Petitioner argues that if a federally-assisted hospital withholds surgery to correct the intestinal problem solely on the basis of the child's anticipated mental retardation, when the hospital would perform the surgery for a "normal" child, the hospital has "discriminated"

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[2] Petitioner even misstates the facts of that case. At birth, the infant known as "Baby Doe" was preliminarily diagnosed as having a deformed heart. Although an autopsy on the child ultimately indicated no heart problems, at the time that the treatment decisions were being made, the potential heart defect was a serious consideration. *See* Pless, *The Story of Baby Doe*, 309 New Eng. J. Med. 664 (Sept. 15, 1983).

against the child "solely by reason of his handicap" in violation of Section 504. Brief for Petitioner ("Pet. Br.") at 15.

Petitioner's hypothetical application of Section 504 is thus premised on a simple, straightforward case in which one of the infant's conditions can be characterized as a "static" disability, and the other as a condition requiring medical treatment. In fact, the vast majority of critically ill infants in pediatric intensive care units who would come under Petitioner's regulations are not so afflicted, but suffer from multiple, interrelated medical conditions, to which the analysis of Petitioner's paradigm case is wholly inapplicable.

Premature infants constitute the largest percentage of infants in pediatric intensive care. These infants, particularly extremely premature infants (24-30 weeks' gestation and one to three pounds weight), may suffer from a multitude of interrelated problems, including: severe asphyxiation at birth; respiratory distress syndrome; compromised intestinal function; heart defects with congestive pulmonary failure; meningitis; septicemia; and immature organs, such as the brain and retina. *See, e.g.*, G. Avery, Neonatology: Pathophysiology and Management of the Newborn 241-55 (2d ed. 1981) ["Avery"]; Stahlman, *Newborn Intensive Care: Success or Failure?* 105 Pediatrics 162, 163-64 (1984).

Besides premature infants, other seriously ill infants suffer from such diverse and often interrelated disabilities as myelomeningocele (spina bifida); hydrocephalus (accumulated fluid in the cranial vault); anencephaly (absence of the cranial vault); and Trisomy 13 and Trisomy 18 (chromosomal defects resulting in a variety of medical disabilities). *See generally* Avery at 870-89, 944-46. For example, "Baby Jane Doe," the infant in *United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984) [*"University Hospital"*], suffered from multiple birth defects, includ-

ing: microcephaly, an abnormally small head; hydrocephalus; inability to close her eyes or achieve sucking action; a malformed brain stem; upper extremity spasticity; and a thumb implanted in her fist. *Id.* at 146. In contrast to the hypothetical infant relied on by Petitioner, seriously ill infants do not present simple, straightforward treatment decisions which can be viewed as involving any sort of "discrimination."

B. Medical Decision Making Does Not Involve Isolated Treatment Decisions

In Petitioner's paradigm case, the pediatrician need only make one treatment decision: whether to perform surgery to correct an intestinal problem. *See* Pet. Br. at 15. Yet just as seriously ill infants do not suffer from static, isolated medical conditions, medical care of seriously ill infants rarely involves an isolated decision to treat one malady. Rather, pediatric care involves numerous treatment decisions which are typically based on an uncertain prognosis. Arras, *Toward an Ethic of Ambiguity*, 14 Hastings Center Report 25, 27 (Apr. 1984). The pediatrician must assess, often without reliable medical data, the likelihood of successful treatment, the risk of damage to the infant from the therapy, the effect on the child of protracted artificial life-support care, and the pain and suffering of continued treatment. Treatment may be life-saving, but the result of the therapy could cause other damage. For instance, use of mechanical ventilation with high levels of oxygen on a premature infant can cause blindness, a scarred trachea or severely damaged lungs. *See* D. Vidyasagar & A. P. Sarnaik, Neonatal and Pediatric Intensive Care 350 (1985); Avery at 13.[3]

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[3] Treatment of premature infants in particular requires an individualized assessment of all of the infants' complex and constantly changing medical conditions, including the immaturity of many organs:

The physician's ability to determine the child's prognosis is complicated by the child's constantly changing medical conditions—what the *University Hospital* court termed the "fluid context of medical treatment decisions." 729 F.2d at 156. The medical conditions of seriously ill infants can change minute to minute and hour to hour, often evading certain prognosis. *See* Avery at 13. The President's Commission for the Study of Ethical Problems in Medicine and Bioethical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment (1983) ["President's Commission Report"] observed that "[f]requently . . . the prospect of long term survival and the quality of that survival remains unclear for days, weeks, and months, during which time the infants may have *an unpredictable and fluctuating course of advances and setbacks.*" *Id.* at 221 (emphasis added).[4]

Petitioner's argument that withholding medical treatment from a disabled infant "subject[s] . . . [the infant] . . . to discrimination" within the meaning of Section 504 thus grossly oversimplifies the medical decision-making process. The spectrum of medical conditions involved, and the numerous medical decisions necessary to respond to them, change continually. The result, as explained by the Second Circuit, is that:

> [w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory."

> The major therapeutic challenge in managing these very immature infants is not so much the specific treatment of disease entities as it is the control of the many pathophysiologic derangements resulting from prematurity itself.

Avery at 241.

[4] Indeed, in its brief in *University Hospital*, the government conceded this point, arguing there that it needed constant access to updated medical records because "[m]edical decision making is a dynamic process." Brief for the United States in *University Hospital* at 24.

University Hospital, 729 F.2d at 157. The treatment decision posited by the Secretary is a simple one; the reality is a far more complex one where differing medical conditions justify different treatment for individual infants. *See* Arras at 26. Thus, a decision which may in Petitioner's view constitute "discrimination" at one moment may become a bona fide medical judgment—concededly outside the scope of Section 504—the next. With the threat of federal intervention, adverse publicity, litigation, and possible loss of funding, the effect of the regulations would be to require treatment even where contraindicated, a gross intrusion into difficult and complex medical decisions.

II. REGULATING THE MEDICAL TREATMENT OF SERIOUSLY ILL INFANTS EXCEEDS THE SCOPE OF SECTION 504

Section 504 is generally designed to assure meaningful access by otherwise qualified handicapped individuals to federally-funded programs. *See Alexander v. Choate*, 105 S. Ct. 712, 721 (1985). The language of the statute and the case law interpreting it uniformly establish that it has a limited scope. First, it only prohibits discrimination against "otherwise qualified" handicapped individuals. Second, Section 504 only prohibits discrimination under a program or activity receiving federal financial assistance. Third, the provision cannot be interpreted to impose unwarranted affirmative action burdens on providers. Petitioner's expansive reading of Section 504 ignores each of these limitations.

A. A Seriously Ill Infant Is Not An "Otherwise Qualified" Handicapped Individual

This Court, in *Southeastern Community College v. Davis*, 422 U.S. 397, 406 (1979), held that an "otherwise qualified" individual within the meaning of Section 504 is "one who is able to meet all of the program's requirements in spite of his handicap." In the context of health

services, Petitioner argues that if a hospital offers a particular treatment that the infant requires, then the infant is "otherwise qualified," as long as such treatment would be "medically beneficial." Pet. Br. at 22-24. Petitioner suggests that a determination of medical benefit is easy because it is "the sort of judgment that health care professionals are accustomed to making on behalf of all of their patients." Pet. Br. at 25-26. Petitioner's interpretation of the "otherwise qualified" statutory requirement, however, completely ignores the complexity of such medical judgments.

First, "medical benefit" has no intrinsic meaning. Whether a particular child would "medically benefit" from a particular course of treatment depends on that child's prognosis, and is therefore inherently individualized—hardly a "bona fide standard" of "general applicability" which Petitioner admits is the relevant determination of "otherwise qualified" under Section 504. *See* Pet. Br. at 22. As Judge Gesell stressed in *AAP v. Heckler*, "*there is no customary standard of care* for the treatment of severely defective infants." 561 F. Supp. at 400 (emphasis in original).

Second, as noted above, a seriously ill infant's medical conditions are constantly changing. Given the "fluid" nature of these medical conditions, during one hour an infant could be deemed "otherwise qualified" because treatment would be "medically beneficial," but the next hour fail Petitioner's "otherwise qualified" test because treatment would be futile or merely temporarily prolong the act of dying. *See* 45 C.F.R. Pt. 84, App. C ¶ (a) (2) (J.A. 122).

Petitioner is unable to respond to the inherent difficulty of determining whether a seriously ill infant is "otherwise qualified" given the reality of constantly changing medical conditions. Petitioner argues that federally-funded educational or physical rehabilitation pro-

grams, which are clearly covered by Section 504, also must account for fluctuations and developments in a child's physical and mental condition. Pet. Br. at 26 n.15. The two situations are easily distinguishable. First, while the child's mental or physical conditions may fluctuate in an educational setting, the fluctuations are not life-threatening, and do not change on a minute-by-minute basis. More importantly, decisions in the educational setting are made by schools and teachers, and *not*, as under Petitioner's final rules, by the federal government. Generally, the role of the federal government has been to ensure that schools have programs available which will respond to the individual needs of handicapped students. There can be no question that the health care services available for the treatment of seriously ill infants satisfy that test. The Secretary wishes to go much further in the hospital context than making sure services are available; rather, she would intrude into individual treatment decisions—a role beyond the scope of Section 504.

B. Medical Treatment Decisions Do Not Involve "Discrimination" By A Federally-Assisted Program or Activity

Petitioner also fails to make out a case of discrimination. Section 504 by its plain language only prohibits discrimination against handicapped individuals "under a program or activity receiving federal financial assistance." Petitioner concedes she cannot regulate *parents'* decisions concerning treatment for their children, because parents are not recipients of federal financial assistance. 45 C.F.R. Pt. 84, App. C ¶ (a)(4) (J.A. 122). She has retreated, therefore, to postulating a case whereby a federally assisted *hospital* potentially discriminates against critically ill infants. Petitioner argues that if a hospital "refused to furnish treatment to a handicapped infant, even though it would furnish the treatment to a nonhandicapped child, the infant has, 'solely by reason of his handicap,' been 'denied the bene-

fits of' and been 'subjected to discrimination under' the federally assisted program." Pet. Br. at 13. Alternatively, Petitioner argues that, where the parents have withheld their consent to treatment, the hospital's refusal to notify the state child protective services ("CPS") agency or to petition a state court for an order directing treatment, subjects the handicapped infant to discrimination under the hospital's federally-assisted program if the hospital would have undertaken such efforts for other children in similar circumstances. *Id.*

Petitioner's argument again is divorced from medical reality. Petitioner can point to no case—because no case exists—where a *hospital* has refused to treat a handicapped child against the wishes of the parents and the treating physician. Hospitals are always prepared to render services when the parents, in consultation with the treating physician, determine that treatment is medically indicated. In *University Hospital*, for example, the hospital was at all times willing to perform the treatment at issue, but lacked the legal authority to do so without parental consent. *University Hospital*, 729 F.2d at 148. If requiring hospitals to make treatment available is the focus of Petitioner's application of Section 504, she has no basis for imposing any regulation, for the "problem" simply does not exist.

Recognizing that she cannot directly regulate parental treatment decisions, and identifying no case where a hospital refused to treat a disabled infant against the wishes of the infant's parents, and, finally, conceding that hospitals lack the legal authority under state law to treat an infant *sua sponte* without parental consent, Petitioner is forced to make a different argument: that a hospital would violate Section 504 not by any act or omission in treatment but instead if it refused to execute its duty under state law to report to the state CPS agency known or suspected cases of unlawful medical neglect. Pet. Br. at 13; *see* 45 C.F.R. § 84.55(c) and 45 C.F.R.

Pt. 84, App. C, ¶ (a)(4) (J.A. 122). There are several problems with this tortured analysis.

First, the legislative history of Section 504 is devoid of any indication that Congress intended a *federal* statute to enforce a recipient's *state* law duties. *See infra*, pp. 18-25. Section 504 was intended to require recipients of federal funds to provide access to the programs and activities for which the recipient receives such funds. *Alexander v. Choate*, 105 S. Ct. at 721. Here, Petitioner construes Section 504 to require the hospital to provide access to a "program" wholly beyond its federally-funded program of furnishing health care—state administrative and judicial proceedings.[5]

In *Bell v. Board of Education, Akron Public Schools*, 683 F.2d 963, 968 (6th Cir. 1982), a case arising under Title VI of the Civil Rights Act in the context of school desegregation, the Sixth Circuit held that where there had been discriminatory practices by federal and state housing authorities, it would place "too heavy a burden" on the school board to require the board to go beyond the scope of its program (education) to remedy discrimination by another program (housing). *See also Goldsboro Board of Education v. Wayne County Board of Education*, 745 F.2d 324, 328 (4th Cir. 1984) ("[a]n independent school district which has not caused segregation in a neighboring independent district has no duty to rectify a racial imbalance in the other district"). Similarly, Section 504 prohibits discrimination and requires remedial action only within the hospital's own program, i.e., furnishing health care.

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[5] This Court has recognized that simply because an entity receives federal funds does not mean that every action taken by that entity is subject to Section 504. Rather, the antidiscrimination prohibition only applies to the "program or activity" receiving federal funds. *Grove City College v. Bell*, 104 S. Ct. 1211, 1220-22 (1984). Petitioner does not suggest, and certainly has no administrative record to support any contention, that federal funds are provided to hospitals to support their reporting duties.

Second, Petitioner cites no evidence that hospitals are ignoring their state reporting duties. Even in Petitioner's paradigm case of Bloomington "Baby Doe," when the infant's parents decided to withhold surgery, the attorney for the hospital promptly notified the county circuit court to arrange for a hearing. *In re Infant Doe*, No. GU 8204-004A, slip op. at 2 (Monroe County Cir., Apr. 12, 1982), *writ of mandamus dismissed sub nom. State ex rel. Infant Doe v. Baker*, No. 482 S 140 (Ind. May 27, 1982), *cert. denied*, 104 S. Ct. 394 (1983). *See also* Holder, *Parents, Courts and Refusal of Treatment*, 103 Pediatrics 515, 516 (Oct. 1983). In Petitioner's preamble to the final rule, she describes numerous instances where hospitals, on their own initiative, notified the state CPS agency pursuant to state law, but she was unable to point to even one case where a hospital failed to invoke such procedures. *See* 49 Fed. Reg. 1646-49 (J.A. 96-106). The "problem" Petitioner identifies simply does not exist.

Third, and most important, the need to ensure proper reporting of medical neglect was directly addressed in the Child Abuse Amendments of 1984. *See infra* pp. 19-22. Congress' enactment of specific legislation building on existing state procedures for dealing with child abuse and neglect indicates its determination that such procedures already protect child welfare. Petitioner's interpretation of Section 504 to permit intrusive federal investigation and enforcement of this state law function is thus unnecessary, duplicative and potentially disruptive to furnishing pediatric care.

C. The Regulations Unnecessarily Intrude Into Medical Treatment Decisions And Would Improperly Require Affirmative Action By Hospitals

This Court also recognized in *Davis* that "neither the language, purpose, nor history of § 504 reveals an intent to impose an affirmative-action obligation on all recipients of federal funds." 442 U.S. at 411. In *Davis*, a licensed

practical nurse contended that her denial of admission to a college nursing program on the basis of her hearing disability violated Section 504. As part of her argument, she asserted that regulations implementing Section 504 required that the nursing program be modified to accommodate her, to which this Court replied:

> If these regulations were to require substantial adjustments in existing programs beyond those necessary to eliminate discrimination against otherwise qualified individuals, they would do more than clarify the meaning of § 504. Instead, they would constitute an unauthorized extension of the obligations imposed by that statute.

Id. at 410. This Court thus distinguished the provision of equal opportunity from affirmative action, stating that "[t]he language and structure of the Rehabilitation Act of 1973 reflect a recognition by Congress of the *distinction between the evenhanded treatment* of qualified handicapped persons *and affirmative efforts to overcome the disabilities* caused by handicaps." *Id.* (emphasis added). This Court found that Section 504 does not require institutions to take substantive steps outside of their ordinary programs to eliminate or overcome handicaps. *Id.* at 413. *See also Doe v. New York University*, 666 F.2d 761, 775 (2d Cir. 1981) (school "not obligated by the Act to alter, dilute or bend [its admission standards] to admit the handicapped applicant").

This Court has also recognized that Section 504 must be kept "within manageable bounds." *Alexander v. Choate*, 105 S. Ct. at 720-21 n.20. Further, it cannot serve as a basis for a "burdensome . . . mandate" on federally-assisted activities or programs. *American Public Transit Association v. Lewis*, 655 F.2d 1272, 1278 (D.C. Cir. 1981). Petitioner's rules constitute exactly the kind of burdensome and disruptive measures against which these decisions cautioned. Under Petitioner's rules, nonmedical teams of HHS employees, designated by HHS as

"Baby Doe Squads," are granted expedited access to investigate reports of suspected discriminatory treatment of infants, including anonymous reports to HHS' "hotline." *See* 45 C.F.R. § 84.55. In *AAP v. Heckler*, Judge Gesell concluded that the intrusion of these "Baby Doe Squads" imposed unwarranted burdens on hospitals, and endangered the health of the infant:

> [A]ny anonymous tipster, for whatever personal motive, can trigger an investigation involving immediate inspection of hospital records and facilities and interviewing of involved families and medical personnel. In a desperate situation where medical decisions must be made on short notice by physicians, hospital personnel and often distraught parents, the sudden descent of "Baby Doe" squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment, can hardly be presumed to produce higher quality care for the infant.

AAP v. Heckler, 561 F. Supp. at 399 (footnote omitted).

Judge Gesell's conclusion that the quality of care suffers from such intrusive federal regulations is well documented. In one instance at Vanderbilt University Hospital, a "hotline" call alleged—without basis—that the hospital was not providing proper care to ten children. The call resulted in a time-consuming and disruptive Baby Doe squad investigation that took 39 hours from doctors and nurses who would have otherwise spent their time caring for patients.[6] Moreover, the investigation disrupted the medical care given the ten patients involved. One child's surgery had to be postponed and another remained in the pediatric intensive care unit

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[6] Affidavit of Norman B. Urmy, Director, Vanderbilt University Hospital, ¶ 10 (J.A. 185).

longer than necessary because the HHS investigators held necessary medical records.[7]

In another instance, an anonymous "hotline" call was triggered by a newspaper article stating that conjoined twins at Strong Memorial Hospital at the University of Rochester might not survive. The call led to a disorganized and time-consuming investigation by a Baby Doe squad.[8] The investigators argued among themselves as to which HHS office was entitled to the medical information, and then flew in a Virginia neonatologist without having even obtained the parents' consent to examine the children.[9] Although HHS investigators later confirmed that the care provided was exemplary, they refused at the time to issue a public statement retracting their allegations that would counter the trauma experienced by parents and the community from newspaper reports of the incident. The unwarranted investigation created fears in parents of other critically ill children as to the adequacy of the hospital's care, prompting one family to have its seriously ill child discharged—based on the unfounded fear that the hospital was intentionally harming children—before treatment was complete.[10] Clearly Congress did not intend Section 504 to authorize intervention which would harm the very individuals it is purporting to protect from discrimination.

In *AAP v. Heckler*, Judge Gesell observed in invalidating Petitioner's interim rule that "many highly relevant factors central to any application of Section 504 to medi-

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[7] *Id.* ¶ 11 (J.A. 185).

[8] Affidavit of Paul M. Rosenberg, Associate Director, Fiscal & Administrative Services, Strong Memorial Hospital, University of Rochester, ¶ 16 (J.A. 178).

[9] ¶¶ 8-13 (J.A. 179-80).

[10] ¶ 16 (J.A. 181).

cal care of the newborn infants were not considered prior to promulgation of the challenged rule." 561 F. Supp. at 399. Despite renewed rulemaking proceedings and slightly modified final rules, Petitioner to date has still failed fully to consider or address the serious implications of her rules, including the disruption, delay, and complications of federal investigators intruding in ongoing treatment of seriously ill infants, and the risk of painful overtreatment.[11] The regulations promulgated under Section 504 require just the sort of affirmative burden and disruption to federally-assisted programs which this Court has repeatedly found to be beyond Congress' intention in adopting Section 504.

III. CONGRESS DID NOT INTEND THAT SECTION 504 SERVE AS THE BASIS FOR FEDERAL INTERVENTION IN INDIVIDUAL MEDICAL TREATMENT DECISIONS

The expansive reading of Section 504 urged by Petitioner is also unsupported by the statute's legislative history and Congress' subsequent legislation concerning treatment decisions involving seriously ill infants. Equally unpersuasive is Petitioner's attempt to find congressional support for her interpretation by analogy to other statutes. Petitioner cannot cite any evidence that Congress intended Section 504 to authorize intervention in the critical care nursery in the manner contemplated by her rules.

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[11] *See* Affidavit of Hubert A. Ritter, M.D., obstetrician-gynecologist and clinical professor at St. Louis University School of Medicine, submitted by the American Medical Association in the Joint Appendix of American Hospital Association v. Heckler, Nos. 84-6211, 84-6213 (2d Cir. 1984) at 155 ¶ 10 (regulations encourage physicians to recommend over treatment in particular cases to avoid investigations as to whether the failure to offer treatment constitutes "discrimination," even though such treatment may not be in the best interest of the child).

A. The Child Abuse Amendments Represent Congress' Belief That Medical Treatment Decisions Regarding Seriously Ill Infants Are Best Addressed Under Existing State Mechanisms

The only occasion on which Congress has specifically addressed the subject of medical care of seriously ill infants is in the Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 *et seq.* ["Amendments"]. The Amendments demonstrate Congress' belief that medical treatment decisions regarding seriously ill infants should be dealt with under existing state administrative and judicial procedures. Under the Amendments, to receive grants for its CPS system, a state must establish procedures for: (1) consultation with designated individuals in hospitals; (2) notification of cases of suspected medical neglect (including instances of withholding of medically-indicated treatment from disabled infants with life-threatening conditions); and (3) legal remedies, under state law, for the CPS agency to prevent the withholding of medically-indicated treatment frob disabled infants with life-threatening conditions. Section 122 of the Amendments, 98 Stat. 1752-53 (amending 42 U.S.C. § 5103(b)(2)(K)).[12] Petitioner admits that these proce-

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[12] The Secretary has issued final regulations implementing the Amendments. 50 Fed. Reg. 14878 (Apr. 15, 1985). Pursuant to the Amendments, the Secretary also issued Model Guidelines for Health Care Providers to Establish Infant Care Review Committees ("ICRCs"). 50 Fed. Reg. 14893 (Apr. 15, 1985). *Amici* strongly support the establishment of review committees and bioethics committees to provide consultation and to ensure that sensitive treatment decisions are made in a reasoned, informed and caring manner. The President's Commission Report also recommended intra-institutional ethics committees to review treatment decisions involving seriously ill infants. President's Commission Report at 226-27 (J.A. 190-91). According to the Academy's 1984 survey of ICRCs attached as Appendix II to Comments of the American Academy of Pediatrics (Feb. 8, 1985) on Proposed Rule Regarding Child Abuse and Neglect Prevention and Treatment Program and Interim Model Guidelines for Infant Care Review Committees, 49 Fed. Reg.

dures are similar to regulations promulgated under Section 504, the authority for which is at issue here. Pet. Br. at 8 n.5.

The Amendments must be viewed in the context of what Petitioner has conceded was an "extraordinary effort" to enact legislation in this most sensitive area. 50 Fed. Reg. at 14879. In *AAP v. Heckler*, Judge Gesell struck down the first "interim final rule," finding that HHS lacked a rational factual basis for the rule and that the agency had failed to follow required notice and comment procedures. 561 F. Supp. at 403. Judge Gesell cited numerous shortcomings in the rule, including the disruptive effect of HHS' enforcement procedures in caring for disabled newborns. *Id.* at 399. He also suggested that this issue "be clarified by further congressional action." *Id.* at 402. HHS then issued a new proposed rule and solicited public comment. While HHS was in the process of preparing its final rule, the case of "Baby Jane Doe" again raised the question of HHS' authority under Section 504 to intervene in medical treatment decisions, which led, after extensive proceedings, to the *University Hospital* decision.

Thus, in the fall of 1984 when Congress adopted the Amendments, it was well aware of the serious legal and policy questions raised by these cases regarding federal regulation of medical treatment decisions.[13] Since the

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48160 and 49 Fed. Reg. 48170 (Dec. 10, 1984), many hospitals already have an ICRC or bioethics committee, and the number of such committees is growing rapidly. Thus, the majority of hospitals which would be subject to Petitioner's rules already have a mechanism, in conjunction with the state CPS system, to review cases of seriously compromised infants and to ensure that when treatment is medically indicated, the infant will receive appropriate care.

[13] *See, e.g.*, S. Rep. No. 246, 98th Cong. 2d Sess. 6-8 (1984), *reprinted in* 1984 U.S. Code Cong. & Ad. News 2918, 2922-25; 130 Cong. Rec. S8956 (daily ed. June 29, 1984) (remarks of Sen. Nickles). The Senate Report noted that "[t]he highly publicized

same congressional committees have jurisdiction over both Section 504 and the child abuse and neglect grant program, Congress could easily have overruled *University Hospital* by expressly amending Section 504 to include coverage of medical treatment decisions concerning disabled infants. Instead, Congress chose to leave such issues to the states, to carry out their traditional role in the area of child abuse and neglect.

As recognized by this Court, the "failure of Congress to alter [a statute] after it had been judicially construed, and the enactment by Congress of legislation which implicitly recognizes the judicial construction as effective, is persuasive of legislative recognition that the judicial construction is the correct one." *Apex Hosiery Co. v. Leader*, 310 U.S. 469, 488 (1940); *see also Blue Chip Stamps v. Manor Drug Stores*, 421 U.S. 723, 732-33 (1975); *Lewis v. United States*, 663 F.2d 889, 891 (9th Cir. 1981), *cert. denied*, 457 U.S. 1133 (1982). Moreover, the same congressional committee that originally enacted Section 504 subsequently defined the scope of the federal role in medical treatment decisions concerning seriously ill infants; as such, that interpretation can be considered "virtually conclusive" as to Congress' prior intended meaning. *Sioux Tribe of Indians v. United States*, 316 U.S. 317, 329 (1942); *see also Socony Mobil Oil Co. v. United States*, 287 F.2d 910, 914 (Ct. Cl. 1961); *accord Abell v. United States*, 518 F.2d 1369 (Ct. Cl. 1975), *cert. denied*, 429 U.S. 817 (1976). Given Congress' clear decision to enact specific legislation governing medical treatment decisions involving disabled infants, Petitioner's contention that there is "firm support" for her interpretation of Section 504 "at every stage of

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recent cases have catapulted the issue of withholding treatment from seriously ill infants into the public arena. . . ." S. Rep. No. 246, 98th Cong. 2d Sess. 6 (1984), *reprinted in* 1984 U.S. Code Cong. & Ad. News 2923.

the evolution" of legislation in this area is mere hyperbole.[14]

B. Congress' Goal In Enacting Section 504 Was To Increase Access To Federally Funded Programs, Not To Intrude Into Individual Medical Treatment Decisions

This Court has recognized that "language as broad as that of § 504 cannot be read in isolation from its history and purposes." *Consolidated Rail Corp. v. Darrone*, 104 S. Ct. 1248, 1254 n.13 (1984). The legislative history of Section 504 demonstrates that Congress did not contemplate federal regulation of medical treatment decisions.

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[14] In the Amendments, Congress adopted a "policy of neutrality" regarding the application of Section 504 to medical treatment decisions involving seriously ill infants. 130 Cong. Rec. S12392 (daily ed. Sept. 28, 1984) (letter from sponsors Senators Hatch, Denton, Nickles, Kassebaum, Dodd and Cranston). The Amendments state that nothing in the statute "is intended to affect any right or protection under Section 504 of the Rehabilitation Act of 1973," Section 127(a), 98 Stat. 1754. Nevertheless, in addressing the issue of medical care of disabled infants, Congress made a specific decision to use the state CPS system rather than authorizing federal intervention.

Moreover, Congress was so sensitive to the painstaking process which led to the enactment of the Amendments that the Senate sponsors prepared a Joint Explanatory Statement describing the statute. In this statement, the sponsors identify the statement as the "definitive legislative history" of the provisions and expressly state:

> Any remarks of individual Senators, including the principal sponsors, on this legislation express only their personal views and do not, therefore, constitute authoritative interpretation or explanation of the measure.

130 Cong. Rec. S8953 (daily ed. June 29, 1984). Accordingly, Petitioner's references to passages in committee reports and debates endorsing the application of Section 504 to treatment decisions of seriously ill infants (Pet. Br. at 45 n.36) do not represent congressional intent and should not be considered by this Court.

In drafting Section 504, Congress initially was concerned with discrimination against handicapped individuals only in terms of employment. *See, e.g.*, 119 Cong. Rec. 24,587 (daily ed. July 18, 1973) (remarks of Sen. Taft on S. 1875, 93d Cong., 1st Sess. 1973)).[15] Later, this goal was expanded in an effort to remove barriers to access in education, transportation, and social services.[16] Contrary to Petitioner's assertion (Pet. Br. at 35-39), that expansion in no way evidences an intent to authorize federal regulation of medical treatment decisions. To the extent that Congress even contemplated "health services" as being subject to Section 504, it did so only in the sense of requiring providers to make such services equally available to all persons able to meet a particular program's requirements despite their disability, a far different situation than the regulation of individual medical care contemplated here. *See* S. Rep. No. 1297, 93d Cong., 2d Sess. 38, *reprinted in* 1974 U.S. Code Cong. & Ad. News 6373, 6388-89. The only specific reference in the legislative history to medicine or health services is in the context of *access* (as opposed to individual treatment decisions) to nursing home services:

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[15] Accordingly, Congress originally defined the phrase "handicapped individual" in terms of employment:

> The term "handicapped individual" means any individual who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services. . . .

Section 7(6), Pub. L. No. 93-112, 87 Stat. 355.

[16] As part of the Rehabilitation Act Amendments of 1974 (Pub. L. No. 93-516, § 111(a), 88 Stat. 1619), Congress expanded the definition to encompass "impairments to major life activities." Under the 1974 amendments, a "handicapped individual" is:

> any person who (A) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (B) has a record of such an impairment, or (C) is regarded as having such an impairment.

> Examples of handicapped individuals who may suffer discrimination in the receipt of Federally-assisted services but who may have been unintentionally excluded from the protection of Section 504 by the references to enhanced employability in section 7(6) are as follows:
>
> * * * *
>
> admission to Federally-assisted nursing homes on the basis of their handicap. . . .

Id.

In sum, no part of the language or legislative history of the Rehabilitation Act of 1973 indicates a congressional concern with individual medical decisions, much less physician and parental decisions concerning complex medical treatment for critically ill infants.[17] In addressing the scope of Section 504 in the context of disparate-impact discrimination, this Court expressly noted that if Congress had intended the statute to reach all such claims, "we would expect some indication of that purpose in the statute or its legislative history. Yet there is nothing to suggest that such was Congress' purpose." *Alexander v. Choate*, 105 S. Ct. at 720. The same is true here. Had Congress intended Section 504 to reach medical decisions, some indication of this intent would be evident in the legislative history. As noted by the Second Circuit, "the failure of congress to focus on treatment decisions involving defective newborn infants strikes a

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[17] In enacting Title XVIII of the Social Security Act (42 U.S.C. §§ 1395 *et seq.*), commonly known as the Medicare program, Congress specifically prohibited "any federal officer or employee" from exercising "any supervision or control over the practice of medicine or the manner in which medical services are provided. . . ." 42 U.S.C. § 1395. Given this broad prohibition in a statute dealing directly with the provision of health care, it is implausible that Congress would have intended intrusive federal interference in treatment decisions in a statute of general applicability.

telling blow to the government's position." *University Hospital*, 729 F.2d at 160.[18]

C. Petitioner's Analogy To Title VI Is Inapposite

Petitioner asserts that by patterning Section 504 after Title VI of the Civil Rights Act, Pub. L. No. 88-352, 78 Stat. 252 (codified at 42 U.S.C. §§ 2000d *et seq.*), Congress intended that Section 504's prohibition against discrimination because of handicap be construed as broadly as Title VI's prohibition against racial discrimination. Pet. Br. at 30-31. Yet the very decisions of this Court cited by Petitioner to support this assertion demonstrate that Section 504 does not incorporate the sweeping prohibition of discrimination on the basis of handicap that Title VI mandates for discrimination on the basis of race. *Alexander v. Choate*, 105 S. Ct. at 717 ("there are reasons to pause before too quickly extending [case law interpreting Title VI] to § 504"); *see also Consolidated Rail*, 104 S. Ct. at 1254 n.13. Indeed, this Court's decisions have recognized that Section 504 does not mandate a total ban on distinctions in federally-funded programs between individuals on the basis of handicap. *See Davis*, 442 U.S. 397; *cf. Community Television of Southern California v. Gottfried*, 459 U.S. 498 (1983) (holding that Section 504 does not require the Federal Communications Commission to alter its standard for reviewing public television license renewal applications to include consideration of the needs of the hearing-impaired).

Moreover, Petitioner proposes an overly simplistic analogy between Title VI and Section 504. Petitioner

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[18] In *AAP v. Heckler*, Judge Gesell also noted that while Section 504 was open to broad interpretation, "no congressional committee or member of the House or Senate *ever even suggested* that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life." 561 F. Supp. at 401 (emphasis added).

argues that Title VI prohibits a federally-assisted hospital from refusing surgery on an infant solely because of his race, and, hence, that Section 504 prohibits the hospital from refusing surgery solely because of the infant's handicap. Pet. Br. at 31, 35-36. This argument ignores the essential differences between race and handicap in the context of medical decision making. First, whereas race is a single factor wholly unrelated to medical treatment, the "handicaps" to which Petitioner refers are multiple medical conditions integrally related to the medical conditions to be treated and are often an essential consideration in the decision as to what type of medical care is appropriate. *See University Hospital*, 729 F.2d at 156.

Second, whereas race is fixed and immutable, an infant's medical conditions are constantly changing. *See supra*, pp. 8-10. Thus, while a decision to deny treatment to a black infant on the basis of race will always be discrimination under Title VI, no such finding of discrimination is possible in the context of medical treatment of a critically ill infant since different treatment decisions must be geared to particular infants and their changing medical conditions. Thus, Petitioner's analogy to Title VI is inapposite.

D. Petitioner's Analogy To A Specific Statute Prohibiting Discrimination In Medical Treatment On The Basis Of Alcohol Abuse Is Inapposite

Petitioner also fails to show support for her Section 504 interpretation by analogy to a specific statute prohibiting federally-funded medical facilities from discriminating in admissions or treatment against alcoholics or alcohol abusers because of their alcoholism (42 U.S.C. § 290dd-2(a)). Pet. Br. at 37-39. Alcohol and drug abuse are fundamentally different types of "handicaps" than the complex set of medical conditions affecting a

seriously ill infant. Alcohol and drug abuse, although disabling in effect, by definition develop from external factors in an individual's environment. Moreover, drug and alcohol abuse are treatable. A disabled infant's "handicap," on the other hand, consists of congenital and acquired impairments, which often are not treatable. To equate alcohol and drug abusers with seriously ill infants simply lacks any rational basis.

More importantly, Petitioner ignores the fundamental fact that Congress enacted a specific statute to address medical treatment decisions involving alcoholics and alcohol abusers, and, by implication, deliberately decided against creation of a specific statute for seriously ill infants. Petitioner apparently suggests that, since Congress has expressly prohibited federally-funded facilities from discriminating against alcoholics and alcohol abusers in furnishing medical treatment, it intended that Section 504 apply to all medical treatment decisions. Pet. Br. at 37-39. That analysis ignores a basic rule of statutory construction that where a statute specifically addresses one form of conduct and the persons to which it refers, all omissions must be construed as exclusions. *See Duke v. University of Texas at El Paso*, 663 F.2d 522, 526 (5th Cir. 1981), *cert. denied*, 105 S. Ct. 386 (1984) ("the absence of a specific prohibition on the discriminatory acts alleged . . . supports an inference that the legislature did not intend to outlaw other acts of employment discrimination by submerging an implied ban elsewhere in the statute"); *see generally* Sutherland, Statutory Construction § 47.23 (4th ed. 1984). Petitioner concedes that Congress enacted "*special* statutory provisions prohibiting discrimination against alcoholics and drug abusers. . . ." Pet. Br. at 41-42 (emphasis added). Since Congress chose specifically to regulate medical treatment involving alcohol abusers but not other patients, it must be presumed that Congress did not intend, in enacting

Section 504, to intrude into other medical treatment decisions.[19]

CONCLUSION

For the reasons set forth herein, the decision of the court below should be affirmed.

Respectfully submitted,

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[19] Indeed, had Congress intended Section 504 to encompass all medical treatment decisions, it would have had no reason in 1974 to extend to all hospitals receiving federal financial assistance the prohibition against discrimination on the basis of alcoholism (Pub. L. No. 93-282, § 121(a), 88 Stat. 130 (codified at 42 U.S.C. § 4581(a) (1970 and Supp. IV 1974)), or, in 1976, further to amend the provision to apply to federally-assisted outpatient facilities (Pub. L. No. 94-371, § 11(a), 90 Stat. 1041 (codified at 42 U.S.C. § 290dd-2(a))). Congress cannot be presumed to have intended to enact redundant and unnecessary statutory amendments. *Uptagrafft v. United States*, 315 F.2d 200, 204 (4th Cir.), *cert. denied*, 375 U.S. 818 (1963).